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Medication Information Seeking Behavior in a Social Context: The Role of Lay and Professional Social Network Contacts

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Abstract

This study provided a view of the social context of medication information seeking from a patient's perspective. This was an exploratory qualitative study with 40 adults to determine how patients communicate within social networks to seek medication information. Semi-structured interviews were used to determine the structure (who), the content provided (what), and the function of social sources of information (how/why). Data underwent ethnographic content analysis using theory and prior research driven themes. Coding matrices were created to identify emerging patterns for who supplied what information and how the information was used. Participants described seeking medication information from health professional or lay social network sources. Health professional sources' strongest role was to provide factual information. In contrast, lay sources provided factual information and affective information such as personal experiences and beliefs or attitudes. Information sought from social sources displayed similar functioning roles in terms of how the information was used by the participants seeking the information. The study concluded that medication information is sought from social sources both inside and outside of healthcare. Emerging patterns found that lay sources may provide patients more than affective information about medications. Further, patients may be receiving factually based information other than from health professionals. By coming to a more complete understanding of the social nature of the information environment, health professionals can better understand information needs from a patient's perspective.

Background

Providers need a complete understanding of how social relationships may influence behavior. There is a social context of health information that impacts a patient's perspective when obtaining, searching for and applying information.^{1,2} Social scientists in health care have often focused on how patients make medical decisions that impact behavior. There are two perspectives in this area, the first being individuals make decisions in isolation. The second is patients consult with others and this interaction ultimately influences decisions.³ This second perspective is known as a social network perspective. A social network can be defined

as a set of relationships among people.⁴⁻⁸ How a social "tie" affects behavior, is a fundamental concept in social network research.⁹ Studies have discussed people tend to place trust in, as well as derive confidence and assurance from, social ties when seeking information.¹⁰⁻¹² Moreover, health communication and information exchange occur outside formal institutions¹³⁻¹⁵ such as physician offices or at the pharmacy counter.¹⁶⁻²⁰ When examining social networks in the context of health, researchers have used the categorization²¹ as either "outside" or "inside" of the health care system.^{22,23} 'Lay ties' described interpersonal relations with those persons outside of the health care system (e.g.

family, friends, and acquaintances). The term ‘professional ties’ referred to the formal contacts “inside” the healthcare system (e.g. physician, pharmacist, or nurse).²⁴

From an individual perspective, health information seeking behavior has been studied in a variety of contexts²⁵ including medication use.²⁶ In addition, research has examined the connection between information seeking and outcomes.²⁷⁻²⁹

Although research has acknowledged social networks to be a rich source of health-related communication,^{5,12,30} it has lacked a focused examination of the interpersonal communications among social sources for medication information.^{18,31-36} In summary, a social network perspective to understand medication information seeking will contribute to describing the social context of health information.

Study Framework

The conceptual framework for this study combined conceptualizations from the topic domains of information seeking behavior and social network perspectives. Various information behavior literature have highlighted sources² of information within the health care environment as well as the types of communication channels.¹ Using these ideas, the current study specifically focused on information sources of ‘lay’ family, friends, peers and the ‘expert’ sources of providers. The current study focused only on interpersonal communication, connecting information source to recipient.

In order to further develop the framework, a model was used from the work of Pescosolido that integrated the network perspective and individual response (2006). This was the “network-episode model.” It recognized the importance of the “life course” experiences, ethnographic nuances of the illness career, and the use of care and advice both inside and outside of the usual health care system.²² The comprehensive nature of this model fit well to the current application. Non-social sources of information such as print resources, online websites, or mass media outlets were considered, but not as a primary objective and therefore will not be discussed. Overall, the conceptual framework for this study combined frameworks from two domains: information seeking behavior and social network perspectives. Figure 1 showed the conceptual framework.

Objectives

This study described how interactions with others contributed to perceptions and experiences related to medication information. The research question for this study was: What is the role of social networks in medication information seeking behavior of patients?

Past research showed structure, content, and function should be considered for determining the role of social networks on individual behaviors,^{9 (p. 18)}. The idea of structure, content and function is similar to Donabedian’s model that describes the structure, processes, and outcomes that are used to assess health care quality.^{37,38} *Structure* was considered among ‘who’ individuals’ social networks provided medication information. The content of interest was predetermined as medication information. *Content* was what ‘flows’ between members of a social network. The content included factual information, attitudes or beliefs about medications. *Function* was considered by describing the purpose, use and decision-making applications.

In addition to structure, content and function, a person’s social network characteristics have been tied to individual characteristics.^{22,39} Therefore, past medication use, attitudes toward medication, and health status were also examined. Given the past literature’s use of structure, content, function, and individual characteristics when investigating social networks, this study used the following objectives to answer the research question: (1) describe the structure of individuals’ social networks that supplies medication information; (2) describe the content that is provided through individuals’ social networks related to medication information; and (3) describe the function of the information that is supplied through individuals’ social networks.

Methods

This was a qualitative study based on semi-structured in-depth interviews with adults. The methodology was chosen based on similar research in the area of health information seeking behavior and social networks.^{13,14,16,21,39-41} The institutional review board at the University of Minnesota approved the study. All participants signed a consent form before the interviews were conducted.

Recruitment & Participants

The research project was conducted over a period of five months in various locations throughout the State of Minnesota. There were three setting types used. These included a primary care clinic located on the University of Minnesota (UMN) Twin Cities campus, community pharmacy locations outside the Minneapolis metro area, and a senior center located in Saint Paul, Minnesota. The recruitment for the study also occurred at each respective site. The first setting located in the primary care clinic, was chosen as a study location because of its location in a large urban medical center. Because of its location, it serves patients with a large range of demographic variables and patients who need highly specialized care provided by a university medical center such as cancer or transplant patients. This setting was located in

Minneapolis, Minnesota. The second setting was community pharmacies outside the Minneapolis Metro area. These sites were chosen based on geographic location. These community pharmacies were used to obtain patients who live in less urbanized areas of the State as well as a strategy to target different demographics than those recruited at the outpatient campus pharmacy. Two pharmacies served as recruitment and interview sites which included locations in Park Rapids and Cold Spring, Minnesota. The third setting was added later in the project when it became clear that older adults were not self-selecting to participate in the study. This site was a senior center located in Saint Paul, Minnesota. Because older adults frequented this location for a variety of activities, recruitment at this location was seen as a strategy to expand the study to include this type of demographic that are often high utilizers of medications. Despite the fact that this location was not specifically health related, as was the previously mentioned sites, this location was a headquarters for local older adults to, among other things, receive information on various health related topics such as Medicare Part D and prescription drug prices. The recruitment process used notices in public posting areas.

Participants were self-selected, volunteering adults. The recruitment of the sample for this study was focused on obtaining a wide range of sample participants. The only inclusion criterion was the participants were at least 18 years of age. The inclusion of adults of all ages and medication experiences was justified for this study because of the exploratory and qualitative nature of the objective. Both breadth and depth of experiences was desired to create a broad description. Further, given the unknown nature for how social informational health sources may differ across, age, gender, health status, experience with medication, etc., an inclusive sampling strategy was desired. The open nature of the recruitment allowed for a range of experiences to provide direction for future research. Participants were provided one \$35.00 gift card as a reimbursement for time and travel. The participants were not contacted after the completion of the one-time interview.

The targeted number of participants was 35 to 50. This target range was based on previous literature with similar methodology^{16,39,41,42} in addition to budget and time constraints. Additionally, interviewing and analysis were considered complete when conceptual saturation was achieved, when no new themes or subthemes were created after a majority of the data had been analyzed. Recruitment was stopped after 40 interviews were completed.

Data Collection

All participants were asked to complete an interview that measured aspects related to the use of social network contacts as a modality to seek medication information. Semi-structured undisguised interviews included a protocol script in order to describe the structure, content and function of the participant's social network with respect to medication information seeking behavior. The outline for the protocol script was guided by a review of relevant theory and previous literature.^{5,9,39,43,44} This review influenced the study framework which described social networks in terms of structure, content and function. Outside researchers and health providers were also consulted prior to using the interview protocol script.

The interviews were designed to align with the study objectives to specifically ask about 'who' people talk to when looking for information about medications, types of information received from these people and what was done with the information after it was obtained. Patient's were permitted to discuss any medication information seeking incidents they could recall including instances that also involved sources such as print materials or digital channels of communication. However, in an effort to maintain focus on the relevant objectives the analysis only described findings derived from patients' discussion of seeking and obtaining medication information through social channels of communication.

As verification for topics covered during interviews, a pilot testing period included four interviews during which question relevance and elicited answers were assessed. Slight modifications to interview structure and questions were made based upon the pilot testing period. A topic outline and examples of questions covered during the interviews were included in Table 1. The interviews were conducted from September 2008 through December 2008. Interviews were conducted at the three settings described previously. They were conducted during normal business hours between approximately 9:00 am and 5:00 pm on weekdays. All encounters consisted of a one-on-one private interview with the primary investigator, who was also a licensed pharmacist in the State of Minnesota. Although medication and medication use were discussed, no consultation or medical advice was provided to participants. Interviews were scheduled to last approximately one hour. All interviews were audio recorded using a digital recording device and used audio playback programming. Each interview began with an initial introduction which consisted of a short briefing. This briefing allowed the interviewer to discuss the purpose of the interview, show the use of the digital audio device, obtain the consent, and allow participants to ask questions. Interviews

were allowed to continue until the subject could not think of anything more to add or when the interviewer felt that the main questions had been answered in depth enough to capture the essence of the subject's medication information seeking behavior experience. Interviews were approximately 30-45 minutes in length, however were allowed to proceed longer if needed. The interviews concluded with a debriefing, in which participants were openly permitted to ask additional questions. Most often participants were interested in the plans for use of the study data, the primary investigator's future career plans, or if their answers had "helped" the project. For a few others, general comments were made about pharmacists or prescription use in society. Both the briefing and the debriefing portions of the interviews were not audio recorded.

Analysis

The chosen analysis for this study was qualitative interpretation which used ethnographic content analysis⁴⁵⁻⁴⁷ and meaning categorization of interview transcript content,⁴⁸ drawing on the principles of constant and theoretical comparisons.⁴⁹ Digital audio recordings of interviews were transcribed by a professional transcription service and the resulting text was visually analyzed in a descriptive and interpretive manner by the primary author. Researcher bias was minimized by processes throughout data collection and analysis that were transparent as to what was obtained from data and how analysis progressed from start to finish. Reliability of results maintained through expert verification of coding and thematic definition corroboration as well as audit tracking from outside reviewers. As is consistent with ethnographic content analysis (ECA), code development and final thematic hierarchy were developed based on findings from previous literature in addition to newly emerging themes.⁴⁵ The strength of ECA is it allows for reflectivity characteristics of ethnographic research but maintains theory-informed systematic approach to the data. Its purpose is for both discovery and verification and requires researcher involvement at all phases of data collection and interpretation. This is in contrast to quantitative content analysis where the purpose is focused on verification, uses pre-structured thematic analysis, and researcher involvement at the level of interpretation.⁴⁵

The unit of analysis was each participant interview. The unit of coding was the responses to the medication information seeking incidents reported during the interviews. In order to organize the narrative accounts given by participants, the conceptual framework of structure, content and function of social network contacts was used as a basis for initial and emerging thematic development. The structure was captured by the "who" among individuals' social networks provide

medication information. The data was initially divided into categories for social network structure according to professional and lay social sources and further divided into subcategories according to type of professional or lay source. Examples of health professionals were physicians or pharmacists. Examples of lay sources included co-workers, personal friends, or family members. When reducing data into the "who" of social network structure described, the entire text of the narrative was included, e.g. the entire surrounding text describing the narrative account of obtaining medication information from a co-worker. If more than one person was described during the selected narrative, it was double-coded into two categories for each social network source. The "content" of interest was predetermined as medication information and was further described by participants. Participants were encouraged to describe the nature of the information. For example, it may have been manufacture supplied information or in contrast, a personal anecdote. A priori themes derived from previous research and expert reviewers were used a starting point for data reduction and were shown within the conceptual framework in Figure 1. "Function" was considered by describing the purpose, use, and decision-making applications to the medication use experience. Participants were asked to describe how the information was used and why the sought out the information. As with structure and content, function related coding also began with a priori categories and were permitted to expand throughout analysis until conceptual saturation.

The unit of coding included linguistics phrases to capture the surrounding context of the thought. For example, as little as one phrase or as much as entire paragraphs were isolated into the coding framework. Once the data were initially organized using the framework of structure, content, and function a second phase of analysis was preformed to uncover emerging patterns and relationships within the data. This phase of analysis used clustering of themes and subthemes to create "coding intersections" within the data in order to explore co-occurring concepts. This phase of analysis followed what is described as a cross-case pattern or coding matrix development of qualitative data.^{50,51} Coding intersections were obtained when search queries were preformed so that information about *who* provided *what* and with *what purpose*. For example, results showed the types of information provided by health professional in contrast to family members. Further, results also showed how information from health professionals was used, in contrast to family members. The qualitative software program, NVivo 8, (© QSR, International 2007) was used for all data analysis.

Results

Participants in this study were adults between the age of 19 and 89 (N=40). The majority of the participants, 70 percent (28/40), were female. Participants were varied with respect to age, highest education, work status, and geographic residence. A total of 15 interviews were conducted at the university setting, 8 at the community pharmacies, and 17 at the senior center. A full summary of participants' general characteristics were included in Table 2.

Themes

The conceptual framework of structure, content and function was used to describe and organize data.

Structure: The structure of social networks described by participants was categorized according to type. Two types of social network contacts were a priori dichotomized into 'lay' and 'professional' as was consistent with previous literature.^{5,24,39,52,53} Within the type 'lay,' subtypes included family, close friend, or acquaintance. Family was coded when a subject spoke of someone who was a relative or spouse. The following was one example of a subject talking about her spouse:

I'd only talk to my husband about it on a very non-technical level; he would be kind of like my check. For example, when I was saying I was cold all the time, after three months, he was like, do you think it could be your medication? So he's more of a non-professional, but he's right on the front line, so he would actually see if there was an issue. (32 year old, female)

Close friend was when a subject referred to speaking to someone close to them, but not a relative. For subjects it was often a co-worker or a friend they have known a long time or had a close relationship with. The following was an example of a subject talking about instances when talking with close friends about medications:

What it does. It makes her tired, and mine makes me tired sometimes too, but then we actually compared notes and found out she was actually taking maybe 100mg of Seroquel a day, and I take 800, and she was like, 'Oh my gosh, how can you function?' I just get used to it, I guess. Just things like that. (42 year old, female)

The third subtype of social network contact coded under 'lay' was titled 'acquaintance.' This was when a subject referred to speaking to someone that they only see on a rare or casual basis, have a weak personal relationship with, or do not know that well. The following was one example of a subject talking about instances when talking with acquaintances about medications:

Mmm-hmm, my friends and colleagues; the people I'm standing in line behind at the grocery store. It's one of those things; people talk about their medications a lot, they really do, especially certain groups of people. A lot of diabetics want to talk about what they're taking for it, whether they're on oral or insulin, or whatever; they just seemed to be more interested in talking about it. (65 year old, female)

Inconsistent case examples were documented and considered during analysis. For the type and subtypes of social network source, coded as 'lay' there were several instances when subjects discussed that they do not talk with their lay social network contacts about medication information. Exploring themes in opposite ways helped provide overall theme development. The following were several examples which provide a contrast in regards to lay social networks sources for medication information:

I don't use anything that's given to me from a person. I only use what's given to me by the doctor, because I'm on so many different medications I have no idea whether that would interfere with anything I'm taking and could possibly cause me to overdose and whatever. No, I do not take anything from anybody other than what I get from my doctor. (66 year old, male)

I don't buy anything on just pure testimonials, but how many times has a friend or acquaintance told you about something, or you hear a personality on television? (58 year old, male)

So there's that stuff and maybe because I'm older there's more of a stigma with depression and mental illness and whatever, that you don't want to admit that. So it is difficult to speak to people about that because they're hesitant to let you know that. (57 year old, female)

I don't talk about that with casual friends. (73 year old, female)

There again, I kind of feel that's a touchy subject when you're out among social people. If it's brought up, yes, then I do mention it, but to volunteer it, unless you know the person real well and know their circumstances, no, I don't say it. (83 year old, female)

Within the type 'professional,' subtypes of nurse, physician, pharmacist, related or friend professional and other emerged.

The following was one example of a subject talking to a nurse about a medication related problem:

I was starting to have these heart palpitations, and it was really nerve-racking, because it felt like my heart was coming out of my chest, and I'm 31 years old, I run all the time, I've never had this problem before. And I didn't think it was the steroid until I called up one of the nurse hotlines that we have for our insurance, and I've actually used that a couple of times, and I've found it to be really helpful, only because, when you're worried, you know darn well if you're really sick you'd just go in. So I was actually home alone, and I called up and talked to her for a while – a long time, actually – and went through all the steps. Finally she asked me, have you started any new medications? And I was like, I did, I took this steroid, and she said it's probably the steroid. She said to give it a couple of days, if it's still there, you might want to go in. (32 year old, female)

The following were examples when subjects recalled a time when talking with a physician about medications:

Well, usually I go to my primary care first if I have a particular issue, and he helps recommend medications. (52 year old, male)

Cost was always an issue when you don't have insurance. I was fortunate to find a doctor that could find something that was more inexpensive and he was willing to look it up for me. (57 year old, female)

The following were examples when subjects recalled a time when talking with a pharmacist about medications:

The pharmacist, like I mentioned, it's more the mechanics of taking the medication. If I haven't taken it before, I make sure that I ask him questions about the dosage. Sometimes I get information from the primary care pharmacist and I relay it to the pharmacist where I pick up my meds and ask him about medication alternatives or pricing or something like that. (52 year old, male)

And then I went and read up a little more and when I picked it up I really talked to the pharmacist downstairs, 'what do I need to be looking for?' With the Prednisone, too, when I picked it up I asked the pharmacist. (50 year old, female)

The following were examples when subjects recalled a time when talking with a professional who was also a relative or friend, about medications:

My mom also works at a clinic, so sometimes I ask her to ask colleagues and then report back to me, and then my uncle's a doctor, so sometimes if I have a medical question... I've asked him two or three times in the past,

but a lot of times I ask my mom to ask questions for me. (25 year old, female)

My dad's a physician, so I would definitely talk to him. (32 year old, female)

My son, is a pharmaceutical chemist developing cancer drugs and other things, so if it seems like he might be a resource. (69 year old, female)

Just looking for it out there in the world of drugs and talking to a friend whose son is a doctor. That's who told me that it's not available anymore. (64 year old, male)

As discussed previously with respect to 'lay' social network sources, exploring themes to demonstrate a contrast to the majority findings helped provide overall theme verification. The following were several examples which provide a contrast to a majority of the coded data that was presented previously in regards to professional social networks sources for medication information:

The big problem is when do you turn your back on a health professional? When do you feel that your understanding of yourself and your situation pre-empts? That's one thing for Christian Scientists; they never do. For me, it's a dilemma. (69 year old, female)

Medicine information, that's very poor from all over. It's just the basics; nobody goes into details. If you don't know about medications like medical professionals do, they leave you with very basic information. They do not go in too deep. It's just take it with food or maybe you'll have an upset stomach. The additional side effects or long-term side effects nobody is telling you. (48 year old, female)

I don't really ask the pharmacist where I pick up my meds that many questions; they're just very specific and short. (52 year old, male)

I can remember getting those two prescriptions filled and coming out of the drug store with a two hundred and something dollar bill, and a hundred and some of this was the Ambien, which could have had a generic for it, and it just seemed like all they were doing was prescribing medications to make money for the pharmacist.

[Interviewer: *They were not very good about telling you about them?*] *No, they did not explain at all what any of these were for. It was just you have to make sure that he had them. (51 year old, female)*

Content: Content themes related to beliefs and attitudes, personal experience, and factual information as well as

function themes related to decision making, monitoring, social support, and validation were consistent with previous literature.^{5,39,54-56} Overall, the content that was provided through social networks related to medication information was described by three general themes and four subthemes. The three general themes included: beliefs and attitudes, personal experience and factual information.

The first theme of content of medication information that was described by subjects was labeled as 'beliefs and attitudes.' This theme was anything that captured if the subject had obtained or considered the opinions or feelings of others with respect to medication information. Below were quotations from three subjects speaking about the content that was supplied in terms of beliefs and attitudes:

And then later on down the road, I was explaining to my mom and stuff, and she'd had issues and she was seeing a psychologist and everything. She was totally against anything like that. She was like, oh, anti-depressants, you're changing your personality, but I didn't care; it made me feel better, so I took it anyway. (28 year old, female)

We don't talk about our particular strategies or tactics about what we have to do. It's more like we just console each other and bitch about it, but we don't really... well, sometimes I'll explain, like I explained to you, to somebody in my situation. I don't know what they do with that information. (52 year old, male)

At the Veteran's Administration, at the Lung Care and Rehab, I talked to just about everyone there about what they were on and what they thought about it. (60 year old, male)

The second theme in content of medication information that was described by subjects was labeled as 'personal experience.' This theme was anything that captured whether the subject had obtained or considered the personal experience of others with respect to medication information. Below were quotations from several subjects speaking about the content that was supplied in terms of personal experience:

I remember one situation where a coworker friend was having trouble with another hospital system. I told them, 'well, this is what I do...' She changed hospitals because the quality of her care for her chronic disease wasn't very good. (52 year old, male)

When I was going to a place called Park House, which is a center for HIV people, and you talk to everyone. Everybody talks to everyone about what they're taking,

how it's working, do you think this will work for me, how long have you been taking it, what kinds of results, it's a constant thing. (42 year old, female)

It was mostly because she's not on the Spiriva, which I could advertise for them I think it's so great. We've talked about that, but her doctor is reluctant to put her on it. We discuss a lot the stress of our breathing, because we exercise together, so we talk a lot about what our breathing is like on a certain day and so forth. (69 year old, female)

The third theme in content of medication information that was described by subjects was labeled as 'factual information.' This theme was anything that captured whether the subject had obtained or sought factual information from others. Factual information was spoken of, in general, however most often subjects spoke of information that was able to be further described into one of four subthemes: adverse effects or interactions, cost or insurance, effectiveness, and use or dosing. Below were quotations from several subjects speaking about the content that was supplied in terms of factual information:

Also in terms of if something was normal or not, like if I was taking medication and I had an embarrassing side effect, I think I might ask a friend that had taken the medication before I went and asked the doctor. (25 year old, female)

There's a pharmacist in primary care where if there's a medication, a particular class of medication and it's an economic situation, I'll go to her to ask for information about alternate resources for getting that medication, or an alternate medication, or, for example, she turned me onto Rx Outreach, which helped me get my Simvastatin at a much more discounted price. (52 year old, male)

We just talk about my medications, how they're working, how I feel taking them, whether I need refills or not, things like that. (42 year old, female)

This one has to do with the dosage and how much I'm going to be taking at one time. It's a one-time thing, and it sounds like an awful lot to be taking at one time, so I want to call and make sure that's correct. Those are the kinds of things I would be asking. (74 year old, female)

Function: The function that was provided through social networks related to medication information was described by seven themes. The seven themes included: decision making, diagnosis, monitoring, prescriptive or recommendation, social support, staying informed, and validation.

The first theme of function that was described by subjects was labeled as ‘decision making.’ This theme was indicated when the person had talked with someone and gained information to specifically apply to a decision. Below were quotations from subjects speaking about the function of medication in terms of making decisions:

And then of course, we talk about birth control, like should I take it or should I not take it, should I go off it? So in that regard, I probably only talk to him, now that I think about it; I only talk to him about that decision. (32 year old, female)

I don’t hesitate to talk to them [the pharmacists] out here. They’ve been just absolutely wonderful, and when they say something, I believe them. In fact there’s a couple drugs that I came in here with and they said, ‘with everything you’ve gone through, I’m not sure that this is actually a large enough dose.’ They would say, ‘let me call your doctor and see if we can’t do better than what this is.’ I had no problem with them doing it. (65 year old, male)

The second theme of function that was described by subjects was labeled as ‘diagnosis.’ This theme was indicated when the person had talked with someone when trying to directly diagnose or treat a medication related problem. Diagnosis was a new theme that emerged during the data analysis. Below were quotations from subjects speaking about the function of medication in terms of diagnosis:

So yeah, anybody that would listen would know about it, because I was just in a tremendous amount of pain daily. I think my boyfriend at the time had to put up with it more than anybody, and probably my friends. My mom of course knew; she was just a mess about it because she had no idea. She was like why can’t they figure out what’s wrong with you? And usually she was pretty good at looking up in the medical dictionary different things; like she’s the one that figured out I had Mono. (28 year old, female)

With the Synthroid, it was really just talking to my physician and my family, because it runs in my family, so we were actually checking it pretty regularly, and then sure enough, I came in for a yearly physical, and it went down, and she was like, bam, you’re starting on it. (32 year old, female)

The third theme of function that was described by subjects was labeled as ‘monitoring.’ This theme referred to a subject who spoke about making sure a decision or course of action was something they wanted to maintain or change. Often, subjects were checking for reasons to change their minds,

exploring possible threats with proceeding as planned, or continually getting a feel for the options that existed within the environment. Below were quotations from subjects speaking about the function of medication in terms of monitoring:

And then there was this cost thing, so I started talking to people, and they were like, oh yeah, my friend had one but it cost like \$500, so then I was like, oh. And did I ever go research any of this? No. Because I never really got to the point where I actually felt it was important enough to make a decision about it; this is more just kind of like canvassing, talking to people. (32 year old, male)

The physician would have been recommending something; there would have been give and take. My daughter would have given input. For example, the dosage would have been – not a negotiation. My daughter as the patient, and my wife and I as the parents, pleading with the physician to downsize or increase – not so much that, but kind of a nitty-gritty discussion about how to set the dosage, experiment a little bit, trial and error for a month or two and see what’s happening, maybe scale it back a little bit after that, maybe increase a little bit after that. Kind of a practical effort to find the best result through initially talking; talking with the physician at an office visit and then having her repeat visits and comparing notes and trying to improvise a little bit, somewhat trial and error, decide what was best. (59 year old, male)

My sister is taking Evista, and she’s had a remission of her osteoporosis, so it’s on my list to confront my poor, beleaguered doctor with. Why this and not that? Have things improved or have they stayed the same? (69 year old, female)

The fourth theme of function that was described by subjects was labeled as ‘prescriptive or recommendation.’ This referred to a subject obtaining a specific recommendation. However, this also referred to getting direction or guidance from a social network contact. Prescriptive/recommendation was a new theme that emerged during the data analysis. Below were quotations from subjects speaking about the function of medication in terms of getting a recommendation:

When I first encountered being told, ‘This is probably what you need,’ because I didn’t know it was depression and that was from a physician, I just went, ‘Mmmm, I don’t know.’ But I was desperate, so I just did it. I just took it. I didn’t research it. I didn’t look at the side effects. At that point I didn’t care about a lot, so it was just that I

had to do something. So that was on their advice and I didn't question it; I just took it. (57 year old, female)

I don't think I would have thought to call my pharmacist and ask them questions; it seems like it's something that's not – I don't think most people do that; I think they call their doctors first, when I think most people know that their pharmacist is probably an easier contact, and they would know just as much or have some suggestions. (19 year old, female)

Then I went to the pharmacy, I got the bottles off the shelf, and I said can you tell me the difference between these two vitamins? Should I take a supplement? Should I take a multi-vitamin? So I got their advice, and I started taking that. (32 year old, female)

Okay, so then just two weeks ago I was complaining about dry skin to a friend. We're getting closer, but we're not really close yet. She told me to take fish oil, so I started taking that. (32 year old, female)

The fifth theme of function that was described by subjects was labeled as 'social support.' This referred to a subject obtaining emotional support from another person with respect to medication or medication use. Below were quotations from subjects speaking about the function of medication in terms of social support from others:

She tells me what she's on, and then I'll tell her what I'm on, but she just doesn't get why I'm on so many different things. She only has a few, so I think she doesn't understand why mine's so severe. I said I have other psychological problems, so there are different issues, but she calls me every once in a while and we talk. She understands why I take them. (31 year old, female)

It was kind of reassuring because she was like, 'I'm sure this is what you have. If you just get the medicine it will go away,' because I was like, 'maybe it's something worse.' I didn't really want to go in to the doctor and be like, 'can you look at my bum?' So I talked to my mom first and she calmed me down and reassured me that maybe you should just try the Preparation H and see what happens. (25 year old, female)

The sixth theme of function that was described by subjects was labeled as 'staying informed.' This theme was indicated when a subject spoke in general terms about wanting to stay up to date or to seek out all the information they could get. They may not have included how they planned to use the information however, the information itself served to keep them informed. Staying informed was a new theme that

emerged during the data analysis. Below were quotations from subjects speaking about the function of medication in terms of staying informed:

I remember he had put me on some medication. I can't tell you what it was; I just remember talking to him about it. I think you have to be aware of what's going on and ask questions. You have to be responsible for yourself. (42 year old, female)

So a lot of the sharing of information with my sisters or cousins is to keep people up to date, to keep people informed. (50 year old, female)

Alternatives, yes, I can listen. I'm very open to listening. I won't accept everything, but yes, let me know. I want to know. I want to be informed. (48 year old, female)

The seventh theme of function that was described by subjects was labeled as 'validation.' This implied that the subject was confirming information with someone else, validating something they already knew or confirming that a decision was the correct one, for their situation. Below are quotations from subjects speaking about the function of medication in terms of providing validation:

As far as dosage, he put me on a really low dose to start; that kind of correlated with what I was learning in school, when I'd write about different anti-depressants. (28 year old, female)

I digest it, homogenize it and then I ask people, you know, 'This is what I'm thinking. Is there any reason I shouldn't do this?' (60 year old, male)

I don't think it really changed my mind. I think it just reinforced what the doctor had told me when we had discussed it, when the doctor had prescribed it for me. I just thought, well, I'm taking the right thing. I didn't really change. (75 year old, female)

When I'd draw the blood for the INR I would go to Rich [the pharmacist] and say, 'Rich, what do you think about that?' He told me, 'I would wait two days,' or 'I would increase 3 or 4.' I said, 'OK, I'll contact my surgeon and he'll receive the results immediately, and then he will tell me what he thinks.' So I would always compare what Rich told me and what he told me. 98 percent, they were on the same track. (48 year old, female)

A summary of final themes and subthemes respective to content and function was provided in Table 3.

Linking Themes

Due to the nature of the research question, and because each medication information seeking behavior incident described by participants was coded according to all applicable components of who, what and how/why (structure, content and function), coding occurrences were double and often triple coded into types, themes and subthemes. For example, if a respondent narrative discussed adverse effect information with his physician that led to changing a dose, it would be coded as physician (structure), factual/adverse effects (content) as well as decision-making (function). Moreover, any one medication information event (a relevant linguistic sequence within a sentence or paragraph) could be coded into multiple themes. This multiplicity of coding allowed for a closer examination of who within participants' social networks supplied what and the how or why participants needed it. This coding strategy allowed for the further expansion of study results into thematic intersections. In order to explore these intersections, computer software was used to assist with the matching of the coded data into cross-case displays or coding matrix development of the qualitative data.⁵¹ The results of the coding matrices for the structure of social networks discussed by participants according to content and function were presented in Tables 4 and 5. Each number presented in these tables represents coded incidents in the data that co-occurred at each respective theme. For example, the number of times participants spoke about medication information seeking behavior incidents regarding 'factual' information occurred within 31 coding instances with physicians and 23 coding instances with pharmacists. All citations at coding intersections were explored to provide further context to understanding social context of the medication information environment. Coding intersections were seen as a synoptic strategy to view data across all cases. Across case analysis has been cited to be useful in qualitative studies using interview techniques, when a comprehensive view is desired.⁵⁷

The Role of Health Professionals

Among professionals, physicians and pharmacists showed the greatest incidences of coding occurrences with themes related to medication information. Nurses and other types of health professionals such as dentists were also mentioned but discussed much less than physicians and pharmacists. Additionally, there were several instances where participants noted talking with 'related or friend professionals' regarding their medications. Professionals that were spoken of by participants predominantly were linked to 'factual' types of information (Table 4). The type of factual information supplied to participants by professionals was varied ranging from effectiveness, use or dosing, adverse effects to cost

types of information. The coding matrixes presented in Table 5 showed how participants viewed the function of medication information from health professionals specified within their social network. Professionals that were spoken of by participants predominantly were linked to 'decisions making.' Other functions of 'monitoring,' 'prescriptive or recommendation,' 'staying informed' and 'validation' were also often linked with professionals. Overall, health professionals presented the fewest coding intersections at themes related to diagnosis and social support. In summary, linking the social network contacts of health professional to both content and function themes showed that health professionals predominately provide content related to factual information, and that participants in turn, used this information to function to make decisions, monitor the information environment, stay informed, take a recommendation, or validate information. Selected citations of health professional coded by content and function themes were included in Table 6.

The Role of Lay Social Contacts

The structural makeup of participants' lay social network contacts was made up of family members, close friends and acquaintances. Family members and close friends showed the greatest incidences of coding occurrences however these incidences were closely followed by acquaintances. According to the coding matrix for lay social contacts and content of medication information (Table 4) 'factual' information and 'personal experiences' themes made up the predominant themes of medication related information content discussed by participants. Though beliefs and attitudes were discussed less than the previously mentioned two themes, they were much more often coded at the 'lay' type of social contact than at 'professional.'

The coding matrixes presented in Table 5 showed how participants viewed the function of medication information from lay social contacts specified within their social network. Lay contacts that were spoken of by participants predominantly were linked to 'decisions making,' 'monitoring,' 'prescriptive or recommendation,' 'staying informed,' 'social support' and 'validation.' Lay contacts were less often linked with 'diagnosis.' Family members showed consistently occurring coding intersections across function related themes with the exception of diagnosis and staying informed. Participants more often spoke of close friends with respect to the 'decision making' and 'monitoring' themes. Participants discussed acquaintances less than the previously mentioned type of lay contacts. Overall, linking the lay social network contacts to content and function themes showed that these contacts predominantly provided content related to factual information and personal

experience, and that participants in turn use this information to make decisions, monitor the information environment, take a recommendation, stay informed or validate information. Selected citations of lay social contacts coded by content and function themes were included in Table 7.

Discussion

Using the framework of structure, content and function, the findings showed the role social networks in the medication information seeking behavior. Structurally, social network contacts were comprised of health professionals such as physicians or pharmacists as well as lay social contacts such as family, friends or acquaintances. In addition, they also included 'related' or 'friend professionals.' Content themes included factual information, information related to personal experiences, and information related to beliefs and attitudes. The function of medication information sought and obtained by patients was used to make decisions, make diagnoses, monitor the information environment, take a recommendation, obtain social support, stay informed, and validate newly acquired or prior knowledge. The conceptual framework for this study was supported by the findings as well as expanded.

Participants viewed medication information from lay contacts differently than the health professionals. In examining Tables 4 and 5, they differed in content of providing information relating to personal experience (52 coding occurrences from lay sources versus 2 from professionals) as well as beliefs and attitudes (20 coding occurrences versus 3). Although content differed, the functioning information role of lay contacts was similar to health professionals except that lay contacts were more often described to provide social support. Although it may seem that the role of health care providers should differ from lay social contacts, one of the most striking findings was that both health professionals and lay contacts provide participants with factual types of medication information. This phenomenon may be a byproduct of health information accessibility to the public. Therefore, it is not surprising patients are talking with and receiving factual information from lay contacts. Although participants in this study did not report talking to health professionals regarding personal experiences or beliefs and attitudes, it remains unknown if patients simply do not expect this information to be discussed by their providers or if receiving this information from lay social contacts fulfills another inherent behavioral need in order to help navigate decisions and experiences during the medication use process. Using the comparison between professional and lay social network contacts helps generate hypotheses for future research. One hypothesis would be that the function provided by social sources, regardless of who provided it, is the same. A second

hypothesis would be the content of the information provided by social sources differs according to who the contact is (lay versus professional), within one's social network. For example, lay social contacts appear to provide a stronger role in providing information that personal experiences and beliefs and attitudes.

The results for this study compare with previous literature that has focused on the role of social contacts and health information seeking behavior. This study was consistent with the finding that participants used interpersonal contacts as sources for medication information⁵⁸ and that participants utilized lay contacts to make decisions with respect to their health care.³⁹ This study adds to the literature showing the important role that lay contacts may have on decision-making through sharing of personal experiences¹⁶ and beliefs and attitudes.²¹

Future research is needed to explore the degree to which information seeking impacts decision making. Research could explore the degree to which patients seek specific information with a purpose to validate a decision in contrast to seeking information that might be opposite to their current course of action. Medication information seeking behavior could be researched with applications to patient-provider relationships. This could determine whether increased seeking correspond to improved relationships. Further, to determine if active information seekers expand content of information sought based on the type of relationship they have with their provider. This study provides the first step toward understanding that 'factual information' is indeed provided by both health professionals and lay social contacts. Future research is needed to determine whether factual information from one source has the potential to outweigh factual information from another source. Finally, this study contributed to understanding the types of medication information that patients require and the communication channels that are used.

Strengths and Limitations

The research findings should only be interpreted with acknowledgment of the theoretical and methodological limitations of the study. Certain aspects of the information environment were not considered. Other health information sources may include health services organizations, government or other public health initiatives.^{1,2} Additionally, the role of the Internet as a source of health information also has been cited to be an influential role in patient health decision making.^{59,60} Other factors that were not considered in this study were contextual factors such as the health care structure or delivery of medication services to patients,

cultural related factors, or type of information seeking behavior such as active or passive seeking patterns.

With respect to the domain of social networks, this study had theoretical limitations. The relationship dynamics between social contacts was not assessed. For example, although people might obtain similar information from social network contact, the dynamics or relationship characteristics, can influence interactions.⁷ These dynamics serve further to classify social network type according to tie “strength” or other relationship characteristics. Additionally, this study did not capture the degree of positive or negative influence social network contacts had on functions of medication information. That is, the actual degree which information assisted in desirable or undesirable clinical outcome. Methodological limitations for this study were related to participant recall bias, researcher bias, and overall transferability. Despite the use of a recall tool⁶¹ and a funneling approach within the interview script, recall bias was still a concern.⁶² It is unknown how far back people consider and it is likely that participants only recalled recent events. Precautions were taken to remove the influence of researcher bias during data collection and analysis. However, despite the transparency of the process, the fact that only one researcher conducted the primary data analysis presents the potential for bias. Overall transferability was a limitation due to the sample size, local population, and self-selecting status of volunteers. It is believed that although the study may not be generalizable to larger populations, that future researchers could potentially transfer the methods used in this study to a study in a similar setting and context and yield similar findings. Finally, because some of the recruitment and interview settings were medically affiliated, the potential for social desirability bias in participants’ discussion of providers and health behaviors was present.

Conclusion

This research found that the role of social network contacts are a source to obtain information related to medications. Further, these contacts may play a role in how patients apply this information. Health providers should be made more aware of a patient’s social environment in order to have a clearer picture for how they can seamlessly align themselves into a patient’s social network. Further, this research can provide health providers a clearer picture of the importance of learning whom patients are getting their information from in order to optimize decision making in the medication use process. In summary, the role of social networks in medication information seeking behavior of patients can be describe in terms of structure, content and function. Patients use social network contacts from both inside and outside of health care to satisfy perceived informational needs. The

noted differences between the content and function of the medication information provided by health professionals and lay social contacts contributes to an understanding of the information seeking patterns and needs of patients. Although health professionals will be unable to prevent patients from seeking information from lay social network contacts, gaining an understanding of the types of information sought from other sources, health professionals can further adapt to offering patients information that goes beyond “just the facts” to help patients relate and shape their overall understanding of the medication use experience. These findings support that patients may not need additional factual information, but instead need help applying factual information to decision making to optimize therapeutic outcomes. Providers must take advantage of their role within the health information environment and adapt to specific information needs of patients. In order to achieve this, providers should develop relationships with patients such that patients feel comfortable discussing all types of medication information they have obtained, from various sources, and respectfully assist patients with applying appropriate information.

In addition to factual information, providers should not be apprehensive to provide patients with anonymous anecdotal accounts of other patients’ successes and problems with applicable drug therapies, as well as to provide professional opinions related to medication therapy. For example, some research has suggested that narrative anecdotes are more effective than statistical evidence for influencing some medication outcomes.⁶³ Lastly, providers should not sway patients from obtaining outside sources of information. This study showed lay interpersonal social network contacts to be actively involved in the medication information seeking process. Creating an environment where patients have a decreased amount of apprehension with disclosing outside information to a health provider has the potential to encourage patient-provider communication and optimize medication use outcomes.

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Figure 1: Conceptual Framework

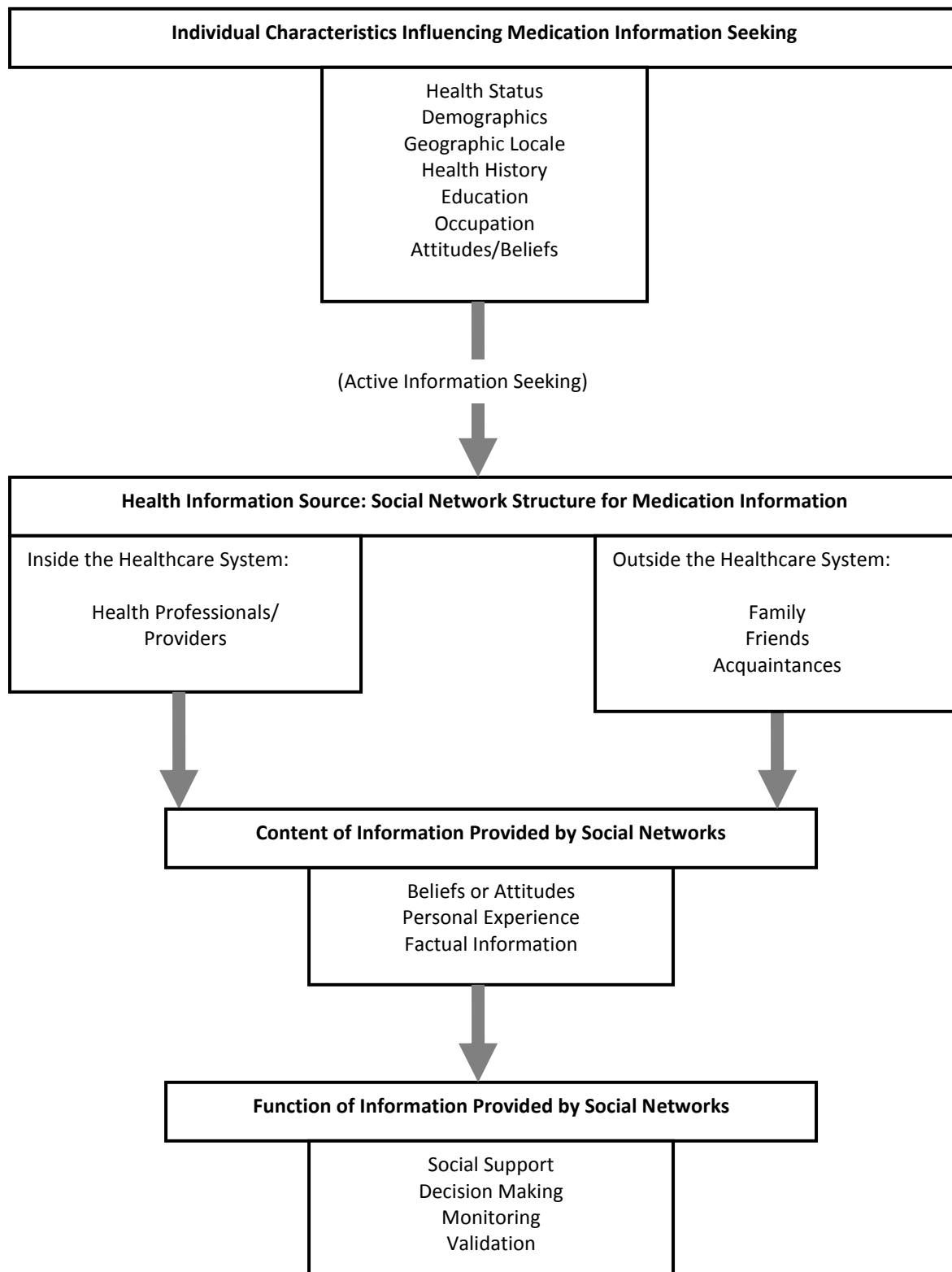


Table 1: Interview Protocol Script

<i>Overall Structure & Description of Interview Script and Example Questions</i>
<p><i>Part I</i></p> <p><u>Individual Characteristics:</u> Demographics such as age, education, geographic residence were collected. Participants were encouraged to briefly discuss their health and/or past medication use to provide a context for the interview. For example:</p> <p><i>Describe your health in your own words.</i></p> <p><i>What medications do you take?</i></p> <p><i>What are your thoughts on the medications you take?</i></p> <p><i>Have they made a negative impact on your life?</i></p> <p><i>What kinds of experiences have you had with your medication treatments?</i></p> <p><i>Part II</i></p> <p><u>Social Network Contacts:</u> Participants encouraged to discuss or draw a visual representation of who were included in their social network. This could include professionals in addition to family and friends. For example:</p> <p><i>Who are the people you talk to most frequently?</i></p> <p><i>When you are in a crisis or must make a big decision, who do you talk to?</i></p> <p><i>With whom do you talk about health matters in general?</i></p> <p><i>With whom do you discuss your medications?</i></p> <p><i>Why do you choose to discuss things with these people?</i></p> <p><i>Part III</i></p> <p><u>Medication Information Narrative Accounts:</u> elicit narrative accounts of medication information seeking behavior experiences including details surrounding who, the type of information, and the function, use, or application of the information. For example:</p> <p><i>Discuss a time when you talked with someone about a medication.</i></p> <p><i>Who did you talk to?</i></p> <p><i>What things did you discuss?</i></p> <p><i>What kind of information were you hoping to obtain?</i></p> <p><i>Was the information for you or someone else?</i></p> <p><i>How did you use the information you obtained from this person?</i></p> <p><i>How did it change the situation?</i></p>

Table 2: General Characteristics of Subjects

<i>Characteristics</i>	<i>(N=40)</i>	<i>(%)</i>
<u>Gender</u>		
Male	12	30.0
Female	28	70.0
<u>Age</u>		
18 - 30	5	12.5
31 - 49	8	20.0
50 - 64	10	25.0
65 +	17	42.5
Range	19-89	
Mean	55.3	
Standard Deviation	18.9	
Median	58.5	
<u>Highest Education</u>		
High School	12	32.5
College	28	67.5
<u>Work Status</u>		
Employed	10	30.0
Unemployed	12	22.5
Student	3	7.5
Retired	15	40.0
<u>Geographic Residence</u>		
Urban	18	45.0
Suburban	9	27.5
Rural	13	27.5
<u>Interview Location</u>		
University Setting	15	37.5
Community Pharmacies	8	20.0
Senior Center	17	42.5

Table 3: Summary for Content and Function Themes

<i>Summary for Content Themes</i>		<i>Summary of Information Function Themes</i>
<i>Themes</i>	<i>Subthemes</i>	<i>Themes</i>
1. Beliefs and Attitudes		1. Decision Making
2. Personal Experience		2. Diagnosis
	3a. Adverse Effects or Interactions	3. Monitoring
3. Factual Information	3b. Cost or Insurance	4. Prescriptive or Recommendation
	3c. Effectiveness	5. Social Support
	3d. Use or Dosing	6. Staying Informed
		7. Validation

Table 4: Coding Intersections: Content by Structure

Coding Intersections: Content By Social Network Structure				
	Factual Information	Direct Personal Experience	Beliefs and Attitudes	Totals
Nurse	3	0	0	3
Physician	31	2	0	33
Pharmacist	23	0	0	23
Related Friend/Professional	6	0	1	7
Other	3	0	1	4
Total Professional	66	2	3^a	71
Family	26	18	9	53
Close Friend	15	21	5	41
Acquaintance	10	13	6	29
Total Lay	51	52	20	123
Totals	117	54	23	194

^a One coding instance was coded at "professional" in general - for beliefs and attitudes

Table 5: Coding Intersections: Function by Structure

Coding Intersections: Function by Social Network Structure								
	Validation	Staying Informed	Social Support	Prescriptive or Recommendation	Monitoring	Diagnosis	Decision Making	Totals
Nurse	0	1	0	2	0	0	0	3
Physician	4	6	1	8	8	3	18	48
Pharmacist	3	2	0	3	1	0	3	12
Related Friend/Professional	1	0	0	0	1	0	2	4
Other	1	0	1	2	1	1	2	8
Total Professional	9	12^b	2	17^c	11	4	25	75
Family	5	3	6	9	10	2	7	42
Close Friend	3	2	3	4	6	1	8	27
Acquaintance	5	3	2	2	3	0	3	18
Total Lay	13	9^d	11	16^d	19	3	19^d	87
Totals	22	21	13	33	30	7	44	162

^b Three coding instances were coded at "professional" in general

^c Two coding instances were coded at "professional" in general

^d One coding instance was coded at "lay" in general

Table 6: Selected Citations Describing the Role of Health Professionals Providing Factual Information

Health Professional: Content Subtheme Function Theme	Citation
Physician Content: Effectiveness & Adverse Effects Function: Staying Informed Physician Content: Effectiveness & Use/Dosing Function: Decision Making	<p><i>Those discussions focused on trying to understand recommendations the physicians were making to prescribe medications; what would be the hope-for, positive effects; what would be the risks or the known adverse effects. (59 year old, male)</i></p> <p><i>My last exam that I saw my doctor, we talked about the cholesterol medication that I'm taking and the osteoporosis medication, and she gave me all the information, how it worked and what was best. I think I asked her about one that I'd heard of that was supposed to be only a once-a-year. You get it once a year. I've seen it advertised on TV, and the once a month type, we talked about that and she seemed to think that the one that I take weekly was the best thing for me, so I continued with that. (75 year old, female)</i></p>
Pharmacist Content: Effectiveness Function: Monitoring	<p><i>If something new comes out, not particular to me or if I hear of a new drug or if I see the commercials because they're all over the TV now, about how something works and I have a question, I'll ask her. Or if I hear of something that was recalled or anything like that, I generally call her right away and she's the first person I call. (32 year old, female)</i></p>
Related Friend/Professional Content: Adverse Effects Function: Validation Related Friend/Professional Content: Use/Dosing Function: Monitoring	<p><i>I've definitely asked my boyfriend [medical resident] questions about antidepressants because one of my... not my best friend, but one of my closer friends was also having side effects, or she thought she was having side effects but she didn't know if it was the result of the medication or not, and so I talked to him and just said, 'is it normal to feel this way?' (25 year old, female)</i></p> <p><i>Yes, the new one out there. I take Fosamex, and there's one out there called Evista that you take once a month. I asked her [nurse/daughter] about that, but no, my doctor would not put me on it. (83 year old, female)</i></p>

Table 7: Selected Citations Describing the Role of Lay Contacts Providing Information

Lay Contact: Content Theme Function Theme	Citation
Family Member Content: Beliefs or Attitudes Function: Validation	<i>But I did feel that the information I got was – talking to my husband, I thought I should bring him in, as kind of the barometer of, yeah, but, remember, you’ve been in a lot of pain with the tooth, and probably good for you to take – he doesn’t know anything about medicine, but just from, ‘well I don’t know, it seems like a good idea, and if you talked to those people, then they probably are right,’ so he kind of was my validator, okay, you’re right, I should take the medication. (32 year old, female)</i>
Acquaintance Content: Personal Experience Function: Decision Making	<i>One of the women said, ‘you know, I haven’t had a period in 20 years and now I have to go back and buy sanitary pads,’ and I said, ‘that’s not for me. I don’t think I want that.’ Just the discussion about it sounded like it was a lot of stuff putting into your body that you didn’t really need if you could get over your hot flashes ... it’s like treating your menopause as a disease rather than as something natural that happens to people. (68 year old, female)</i>
Acquaintance Content: Factual - Effectiveness Function: Validation	<i>Somebody was saying they took one that worked a little differently from the regular statin for cholesterol and that they had problems with it and it wasn’t working that well, so they were seeing which one was the best. I thought, well, I don’t want to take that one because he’s had a bad experience with it. I don’t think it really changed my mind. I think it just reinforced what the doctor had told me when we had discussed it, when the doctor had prescribed it for me. I just thought, well, I’m taking the right thing. I didn’t really change. (75 year old, female)</i>
Family Member Content: Beliefs or Attitudes Function: Decision Making	<i>I was explaining to my mom and stuff, and she’d had issues. She was totally against anything like that. She was like, oh, anti-depressants, you’re changing your personality, but I didn’t care; it made me feel better, so I took it anyway. (28 year old, female)</i>
Friend Content: Factual – Adverse Effects, Use/Dosing Function: Staying Informed	<i>I did talk to my best friend before I went on Adderall because she had been on it since as long as I can remember, and I’d gotten a diagnosis of ADD and was told I should be put on Adderall. I was a little weirded out about it and nervous and wanted to know what it was like, what other kinds of consequences it has. She told me to be really careful and that it does have some pretty bad stuff and it can start interfering with your life and that she doesn’t sleep. She was on way too high of a dose. They figured it out eventually. So she said I need to be very careful about the dosage, too, and make sure that that was being taken care of, and that they didn’t need to put you on any more than you actually needed. (20 year old, female)</i>